

Dementia Friendly Libraries

Montana Public Libraries (Zoom)

February 3, 2023

Patti Holkup and Dan Doyle

MISSOULA *aging* SERVICES

A bit about your presenters

Patti and Dan are volunteers with Dementia Friendly Missoula.

Dan is a retired University of Montana Professor of Sociology where one of his specialty areas was Social Gerontology. He has volunteered for over 30 years in various roles with Missoula Aging Services. He also volunteers at Missoula Public Library.

Patti is a retired Montana State University Professor of Nursing. She taught courses in Mental Health, Family, and Geriatric Nursing. For a little over 10 years, she was a caregiver for her parents and an aunt as they progressed through dementia.

MISSOULA *aging* SERVICES



Dementia Friendly Missoula

Formed in 2015 by a group of committed citizens working to raise awareness of and provide support to individuals and families touched by Alzheimer's Disease or Related Dementias.

Volunteer affiliate with MAS (2018)

Membership in Dementia Friendly America

Community Network (2018)

MISSOULA *aging* SERVICES



Dementia Friendly Missoula

Promoting an informed, supportive,
and inclusive community for people
living with dementia and for those
who care for them.

MISSOULA *aging* SERVICES

EST. 1982

MISSOULA *aging* **SERVICES**

WE'RE PROUD *of* OUR YEARS

337 Stephens Avenue, Missoula, MT 59801 406.728.7682

info@missoulaagingservices.org | missoulaagingservices.org

Missoula Aging Services Mission

**We promote the
independence, dignity, and health
of older adults
and those who care for them**

MISSOULA *aging* SERVICES

Dementia Defined

Alzheimer's is a progressive disease of the brain that destroys brain cells, causing problems with memory, thinking and behavior.

3 progressive phases
-PRE-SYMPTOMATIC: ~20 years w/o symptoms
-MILD COGNITIVE IMPAIRMENT
-DEMENTIA: Early, middle, severe.

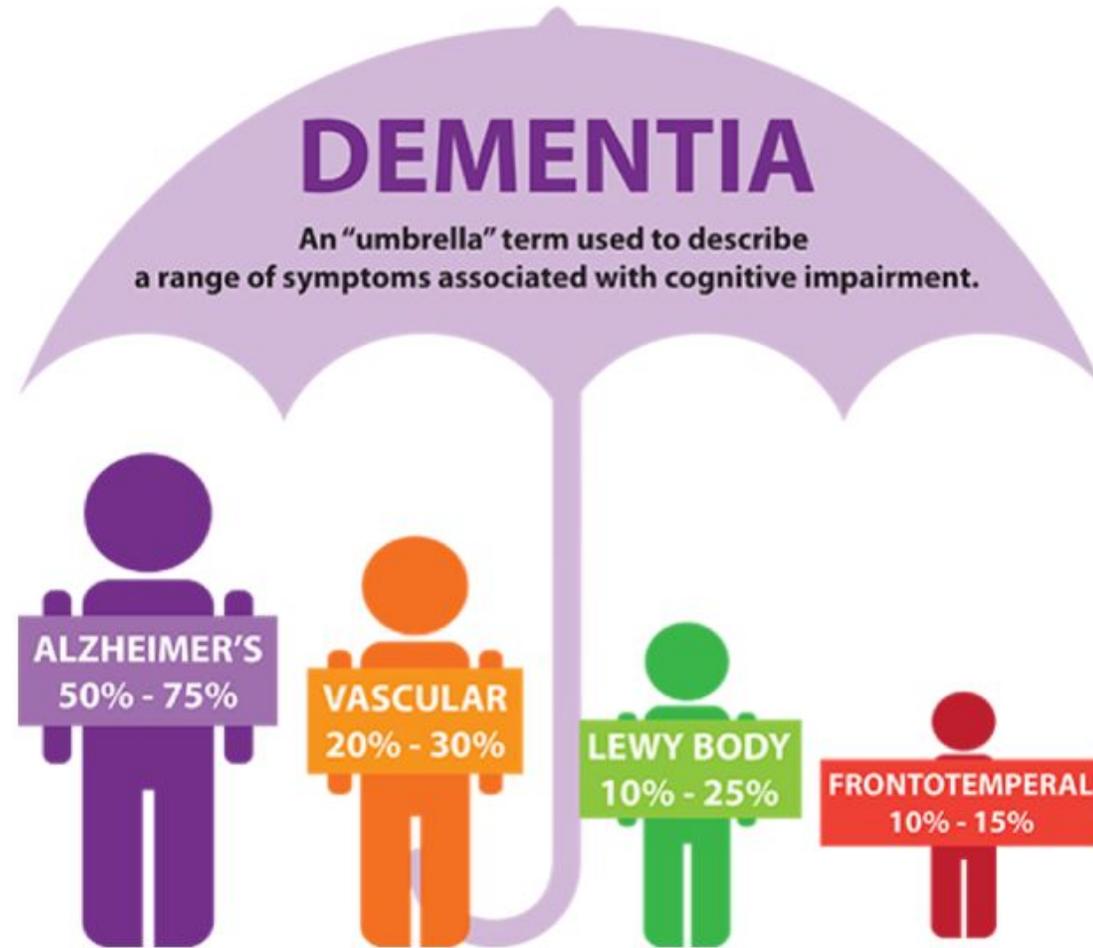


Dementia is a general term used to describe a decline in cognitive functioning such as Alzheimer's disease.

In severe Alzheimer's, cognitive and functional abilities decline: failure to communicate and recognize loved ones, 24/7 care, bed-bound.

Source: MONTANA
ALZHEIMER'S WORKGROUP

Dementia: An Umbrella Term



MIXED DEMENTIA = > 1 NEUROPATHOLOGY—PREVALENCE UNKNOWN

The Good News

Recent research reports suggest **lifestyle changes** that may reduce your risk of dementia regardless of genetic risk

- **Heart healthy diet**
- **Exercise***
- **Keep your mind active***
- **Stay connected***
- **Check your hearing**
- **Treat depression***

- **Control blood pressure***
- **Manage weight***
- **No smoking**
- **Get enough sleep**
- **Head protection**
- **Moderate alcohol use**

Dementia friendly communities can help **address* these risk factors**

Journal of American Medical Association, 2019; International Journal of Geriatric Psychiatry, 2018; Alzheimer's & Dementia, 2018; Journal of Geriatric Psychiatry, 2018; National Academies of Sciences, Engineering, and Medicine, 2017; American Journal of Alzheimer's Disease & Other Dementias, 2018; *Lancet Commissioned Report, 2017, 2020*

The Not-So-Good News

Alzheimer's is a **Public Health** CRISIS

Of the top 10 leading causes of death in the U.S., Alzheimer's is the only one without a way to cure it.

HOWEVER, there is hope for prevention and treatment

1	Heart Disease	29.3%
2	Cancer	23.2%
3	Covid-19	14.9%
4	Cerebrovascular	7.2%
5	Alzheimer's Disease	7.0%
6	Chronic Lower Respiratory Disease	6.8%
7	Diabetes Mellitus	3.8%
8	Unintentional Injury	3.3%
9	Nephritis	2.2%
10	Influenza & Pneumonia	2.2%

Ten Leading
Causes of Death,
Age 65+ All
Races, United
States
CDC (2020)

Accessed 2022: <https://wisqars.cdc.gov/data/lcd/home>

The burden is large

In Montana...

- There are **22,000** people aged 65 and older living with Alzheimer's in Montana
- This number is set to reach as many as **27,000** by 2025. (**22.7% increase**)

Source: ALZHEIMERS ASSOCIATION (2022)



Because life shouldn't end when dementia begins

MISSOULA *aging* SERVICES

Creating a dementia friendly community is about:



- Raising awareness
- Challenging stigma
- Increasing understanding
- Providing education to community sectors

Dementia friendly communities are:

Informed

Safe

Respectful

Foster quality
of life

Empower
citizens with
dementia

MISSOULA *aging* SERVICES

Being dementia friendly means being able to . . .

Recognize

- Recognize the signs of dementia

Communicate

- Communicate effectively with a person living with dementia

Identify & Implement

- Identify and implement dementia friendly practices

Know resources

- Know where to locate dementia resources and support

Support caregiving staff

- Learn how to support caregivers and the benefits of doing so

Living With Dementia

What is important to those living with early stages of dementia?

- Ability to make plans for their future care
- Ability to contribute
- Shopping and eating out
- Connecting to family and friends
- Engaging in daily activities
- Visiting places of worship
- People want to feel at home in their community

Internal barriers for those living with dementia

- Lack of confidence
- Worrying about being confused
- Stigma or lack of understanding
- Worrying about getting lost
- Mobility and physical health
- Not wanting to be a burden

External Barriers for those living with dementia

- Lack of support to continue activities
- Lack of appropriate activities to do
- Lack of adequate transportation
- Missing or confusing signage
- Difficulty recognizing dementia
- Limited knowledge of communication techniques

Reported experiences from people with dementia

- “They spoke too quickly.”
- “ It was too loud.”
- “They talk so much they confuse me.”
- “He wouldn’t even look me in the eyes”
- “She rushed me and I couldn’t think”
- “They treated me like they didn’t care”

Recognizing Memory Loss

MISSOULA *aging* SERVICES

Possible Clues of Dementia

- **Looking or saying they are confused or a bit lost**
- **Difficulty making choices**
- **Searching for something**
- **Speech might be difficult to understand**
- **Difficulty handling money**
- **Difficulty writing or filling out forms**



Helpful approaches

- **Make good eye contact**
- **Friendly smile**
- **Slow speech as needed**
- **One question at a time - one direction at a time**
- **Give them time to respond**

More helpful approaches

- Offer to help
- Try different forms of communication
- Reduce distractions if possible
- Don't take things personally
- Avoid patronizing tone of voice
- *Be Kind...Be Calm...Be patient
Embrace their reality...*

Create a dementia friendly environment

- **Mark entrances and exits clearly**
- **Use colored rugs (not black) they feel less like holes**
- **Design large and easy to read directional signs or arrows**
- **Have family restrooms**



MISSOULA *aging* SERVICES

More for dementia friendly environment

- **Install good lighting**
- **Design quiet areas**
- **Include seating in large spaces**
- **Ensure areas are free of clutter**
- **Use maps**

Caring for Individuals With Dementia

MISSOULA *aging* SERVICES

Caring for an individual with dementia

- **24/7 –Caregiving referred to as the “36 hour day”**
- **Balance between abilities and capabilities**
- **Increasingly complex as dementia progresses**
- **Need for assistance and respite care**

About caregiving staff— Did you know?

1 out of 6 employees are caregivers

60% female; 40% male

25% millennials! (born 1981-1996)



AARP Supporting Caregivers in
the Workplace: A Practical
Guide for Employees (2017)

MISSOULA *aging* SERVICES

Caregiving staff concerns

Emotional

- Feeling stressed, anxious
- Stigma: reluctant to talk to others

Professional

- Fear possibly being viewed as less committed
- Fear colleagues may feel resentful

Financial

- Increased out-of-pocket expenses
- Average \$7,000/year
- They want to work

Health

- Don't have time for own health needs
- Loneliness/isolation risks for CV diseases

Why support caregiving staff?

- Maximize productivity
- Improve employee's physical/emotional health
- Attract/retain talent
- Reduce health care costs/indirect workplace costs

Some supportive measures for caregiving staff

- Leave & flex time policies
- Resources for caregiving help
- Support for caregivers themselves

Impact of Libraries and Literacy on Those Experiencing Dementia as Well as their Care Partners

MISSOULA *aging* SERVICES

Libraries in the Community

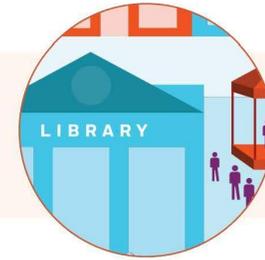
Collection	Books about dementia (for adults & children) Disseminate brochures w/community resources Memory making kits for check out
Outreach	Bringing the library to senior residences
Programs	Memory Cafe, Tales & Travels, provide read aloud times, create poetry, MSU Extension: Using Storytelling to Teach about Alzheimer's
Gathering place	Rooms for activities, quiet spaces, presentations; support groups: care partners, adults w/ dementia

Specific Dementia Friendly Practices for Libraries



Libraries

Libraries are respected community institutions and vital to a dementia friendly community because they provide access to resources, services, and programs for people living with dementia and their families.



What is Dementia?

Dementia is a general term for a loss of memory and other thinking abilities that is serious enough to interfere with activities of daily life. Dementia has many causes. Alzheimer's disease, the most common cause of dementia, is a disease of the brain that leads to problems with memory, thinking, and behavior. Alzheimer's and other dementias are not a normal part of aging.

Warning Signs of Alzheimer's Disease

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, at work or at leisure
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality

Interacting with People with Dementia

- Speak clearly and be patient
- Listen closely
- Smile warmly and make eye contact
- Respond to a look of distress
- Help when confusion is present
- Watch for signs of change and offer help accordingly – every day can be different

Community Resources

MISSOULA *aging* SERVICES

Are you concerned about Memory Loss?



Missoula Resources

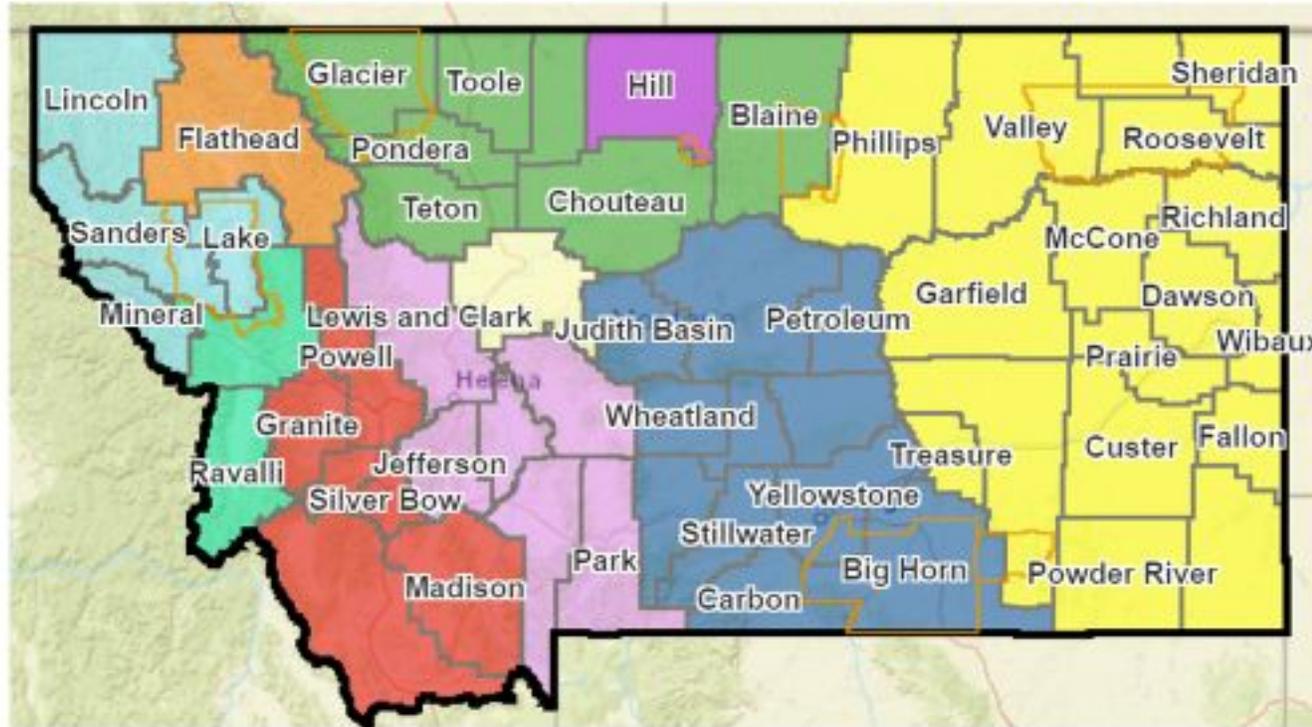
- Missoula Aging Services: 728-7582
- Missoula Public Library Memory Café: 721-2655 (BOOK) or missoulapubliclibrary.org
- Art in the Moment at Missoula Art Museum
- Alzheimer's Support Groups: 728-7582
- Caregiver Support Group: 728-7582
- Memory Loss Conversations (for individuals with memory loss): 728-7582

MISSOULA *aging* SERVICES

State Resources

- Montana's Area Agencies on Aging
<https://dphhs.mt.gov/sltc/aging/areaagenciesonaging>
- Aging & Disability Resource Center, Directory of Resources: www.montana-adrc.org/
- Alzheimer's Association, Montana Chapter:
www.alz.org/montana
- [Montana Alzheimer's and Related Dementias \(ADRD\) State Plan | \(mtalzplan.org\)](http://mtalzplan.org)
- MSU Extension: Resources for Caregivers and Others Concerned About Memory Loss

Montana's 10 Area Agencies on Aging



Accessed 1/2023: <https://dphhs.mt.gov/sltc/aging/areaagenciesonaging>

MISSOULA *aging* SERVICES

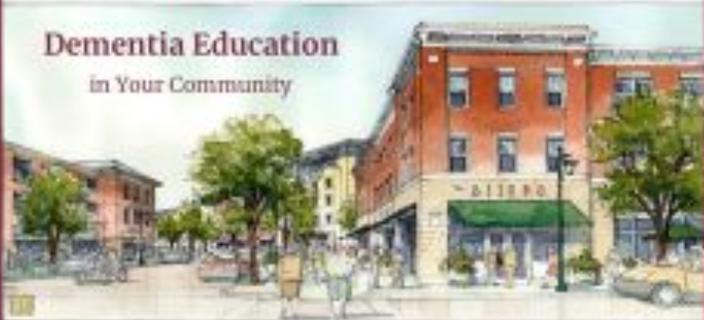
MTGEC Funding Awards

[Funding for Dementia Education in Your Community \(umt.edu\)](https://umt.edu/montana-geriatric-education-center/dementia-funding-mtgec.php) or <https://umt.edu/montana-geriatric-education-center/dementia-funding-mtgec.php>

Applications will open April 1, 2023 and close May 31, 2023 for funds available in the second half of 2023.



Dementia Education
in Your Community



The Montana Geriatric Education Center (MTGEC) is offering awards up to \$2,000 for approved community projects focused on Dementia Education.

Organizations, libraries, senior living communities, Area Agencies on Aging, and others, may use this funding to provide dementia education for healthcare providers, businesses, people living with dementia, caregivers, and community members.



UNIVERSITY OF
MONTANA

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS), as part of a Geriatric Workforce Enhancement Program (GWE) award totaling \$1,750,000 and supports the Montana GWEP 2023. The contents are those of the program and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.

MISSOULA *aging* SERVICES

MSU Extension

- Resources for Caregivers and Others Concerned About Memory Loss
- Using Storybooks to Teach Children and Adults about Alzheimer's Disease

Contact: Local MSU Extension Office or
<https://alzheimers.msueextension.org>

MISSOULA *aging* SERVICES



**Concerned about your recent memory loss?
You're not alone!**

Memory Loss Conversations

**Join us on Zoom Thursdays at 10 am
Meet others adjusting to memory loss
Share conversation**

Questions? Call (406) 728-7682

**Hosted by Dementia Friendly
Missoula**

National Resources

- Alzheimer's Association: www.alz.org/
24/7 Helpline: 1-800-272-3900
- Dementia Friendly America www.dfamerica.org
- National Institute on Aging:
www.nia.nih.gov/health/alzheimers
- National Institute on Aging, ADEAR Center:
www.nia.nih.gov/health/about-adear-center

Best Practices & Webinars for Libraries

- **RUSA Guidelines for Services with 60+ Audience: Best Practices**
<http://www.ala.org/rusa/sites/ala.org.rusa/files/content/resources/guidelines/60plusGuidelines2017.pdf>
- **International Federation of Library Associations and Institutions (IFLA)**
- Guidelines for Library Services to Persons with Dementia -
www.ifla.org/publications/ifla-professional-reports-104
- **IFLA Public Libraries Section Blog: Is your library dementia-friendly?**
blogs.ifla.org/public-libraries/2016/09/07/is-your-library-dementia-friendly/
- **Serving People Living with Dementia: Programs and Interventions to Promote Social Engagement** (Sept 2022)
<https://www.engagingolderadults.org/current-and-past-events>

Best Practices & Webinars for Libraries (cont.)

- **WebJunction Webinar: Remember Your Patrons Living with Memory Loss** (Dec 2022)
www.webjunction.org/events/webjunction/remember-your-patrons-living-with-memory-loss.html
- **Developing a Dementia Friendly Partnership with Your Public Library** (April, 2018)
- **Creating and Sustaining Memory Cafes: Lessons from the Coast and the Heartland** (March, 2019)
[-www.dfamerica.org/news-archives/#](http://www.dfamerica.org/news-archives/#)

References (specific to libraries)

- Bourgeois, Michelle S., *Dementia: Person-Centered Assessment and Intervention* (2018) quoted in “Many Alzheimer’s Patients Find Comfort in Books” by Milt Freudenheim, NY Times 4/2010
- Wilson, Robert S., et al, Cognitive Activity and Onset Age of Incident Alzheimer Disease Dementia (July 2021) *Neurology* n.neurology.org/content/97/9/e922
- Rimkeit, BS; Claridge, G. *Literary Alzheimer’s, a qualitative feasibility study of dementia-friendly book groups.* (2017) *New Zealand Library & Information Management Journal*. Dec 2017; vol. 56(2), pp. 14-22
- Muellenback, JM. *The role of reading classic fiction in book groups for people with dementia is better understood through a qualitative feasibility study (2018).* *Evidence Based Library & Information Practice*. 2018; vol. 13(2), pp 97-98.
- Reading Material for Persons Living with Dementia,
www.alz.org/media/documents/reading-material-for-plwd-rl-2019.pdf

References

- Alzheimers Association (2022). "Alzheimer's Disease Facts and Figures." 18: 1-122.
Accessed at
<https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>
- Alzheimers Association. (2022). Alzheimer's Disease 2022: Facts and Figures. Special Report: More than Normal Aging: Understanding Mild Cognitive Impairment.
Accessed, 01-2023:
<https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>
- Livingston G, H. J., Sommerlad A., et al. (2020). "Dementia prevention, intervention, and care: 2020 report of the Lancet Commission." Lancet 396: 413-446.
- Livingston, G., Sommerlad, A., et al. (2017). "Dementia prevention, intervention, and care." Lancet 390 (December 16, 2017): 2673–2734.
- Lourida, I., Hannon, E., et al. (2019). "Association of Lifestyle and Genetic Risk with Incidence of Dementia." Journal of the American Medical Association 322(5): 430-437.

References (cont)

National Academies of Sciences, Engineering, and Medicine, *Preventing Cognitive Decline and Dementia: A Way Forward*. (June 22, 2017).

<https://nap.nationalacademies.org/catalog/24782/preventing-cognitive-decline-and-dementia-a-way-forward>

National Institute on Aging/National Institute on Health. What is Dementia? Symptoms, Types, Diagnosis. Accessed, 01-2023:

<https://www.nia.nih.gov/health/what-is-dementia>

Northeast Business Group on Health & AARP: Family Caregiving. (2017). Supporting Caregivers in the Workplace: A Practical Guide for Employers. Accessed, 01-2023: https://nebgh.org/wp-content/uploads/2017/11/NEBGH-Caregiving_Practical-Guide-FINAL.pdf

.

References (cont)

- Rosenberg, A., Ngandu, T., et al. (2018). "Multidomain lifestyle intervention benefits a large elderly population at risk for cognitive decline and dementia regardless of baseline characteristics: The FINGER trial." Alzheimer's and Dementia 14(3): 263-270
- Schiepers, O. J. G., Kohler, S., et al. (2018). "Lifestyle for Brain Health (LIBRA): A new model for dementia prevention." International Journal of Geriatric Psychiatry 33: 167-175.
- Thoits, T., Dutkiewicz, A., et al. (2018). "Association Between Dementia Severity and Recommended Lifestyle Changes: A Retrospective Cohort Study." American Journal of Alzheimer's Disease & Other Dementias 33(4): 242-246.